

Frequently Asked Questions

2011 Survey of Pathways to Diagnosis and Services

Updated April 24, 2012

The 2011 Survey of Pathways to Diagnosis and Services (Pathways) is a nationally representative survey about children with special health care needs (CSHCN) aged 6 to 17 years old ever diagnosed with autism spectrum disorder (ASD), intellectual disability, or developmental delay. The questions and answers below summarize key information about the Pathways survey, which is a follow-up survey to the 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN). A detailed report on the design and operation of the Pathways survey is forthcoming and will be released online as soon as possible.

The design of the 2009-2010 NS-CSHCN is similar to the 2001 NS-CSHCN and the 2005-2006 NS-CSHCN. Detailed descriptions of the design and operation of these surveys, as well as descriptions of the publicly available data files and data editing procedures, are published online (<http://www.cdc.gov/nchs/slaits/cshcn.htm>). Similar detail for the 2009-2010 NS-CSHCN is not yet available. However, a "Frequently Asked Questions" document for the 2009-2010 NS-CSHCN has been posted online (<http://www.cdc.gov/nchs/data/slaits/NSCSHCNfaqs2009.pdf>) that highlights changes made to the design and administration of the survey. Users of the Pathways survey data are encouraged to review these documents.

The present document highlights general information that is unique to the Pathways survey design. Please read this document before analyzing the Pathways data.

BACKGROUND

Who sponsored the 2011 Pathways survey?

- The National Institute of Mental Health (NIMH) of the National Institutes of Health (NIH), with funds available from the American Recovery and Reinvestment Act of 2009 (ARRA) (Public Law 111-5).
- The survey is part of NIMH's Pathways to Diagnosis and Services Study.

Who conducted the 2011 Pathways survey?

- CDC's National Center for Health Statistics (NCHS), State and Local Area Integrated Telephone Survey (SLAITS) program.

SAMPLE DESIGN

What was the 2011 Pathways sample design?

- Follow-up survey to the 2009-2010 NS-CSHCN, which was a cross-sectional random-digit-dial telephone survey (landlines and cell phones) of US households with at least one child aged 0 to 17 years at the time of the interview.
- A sample of children with special health care needs (CSHCN) identified as having (or having had) at least one of three developmental conditions (ASD, intellectual disability, and/or developmental delay) was randomly selected from the NS-CSHCN. Their parents and guardians were re-contacted by telephone for the Pathways interview.
- Parents and guardians who completed the telephone interview were then sent a self-administered questionnaire (SAQ) by mail. Parents and guardians who had not returned the SAQ received a reminder telephone call to prompt completion; some parents and guardians completed the SAQ over the phone at that time.
- Because the Pathways survey follows the NS-CSHCN, it shares the complex survey design of the NS-CSHCN, with clustering of children within households and stratification by state and sample type (landline or cell phone). In addition, the random selection of Pathways-eligible children for follow-up was stratified by condition(s) reported in the NS-CSHCN.

How was eligibility determined?

- Telephone numbers for the randomly selected Pathways-eligible CSHCN were called and screened to ensure that the children still met all four eligibility criteria:
 - The respondent who completed the 2009-2010 NS-CSHCN was available to be interviewed for the Pathways interview.
 - The Pathways-eligible child was 6 to 17 years of age at the time of the Pathways interview.
 - The Pathways-eligible child continued to live in the same household as the respondent.
 - The respondent for the 2009-2010 NS-CSHCN confirmed or reported that a doctor or other health care provider had ever said that the child had ASD, intellectual disability, and/or developmental delay.
- If the child no longer met all of the above eligibility criteria, the call was terminated.
- If the telephone number no longer reached the expected NS-CSHCN respondent, additional efforts were made to try to locate the respondent by 1) calling any available telephone numbers for the respondent or alternate contact that were provided during the NS-CSHCN, and 2) performing extensive searches using various Internet sites. If the information did not lead to the NS-CSHCN respondent, the case was deemed not locatable.

How many children were selected as the target of the interview?

- The targeted number of completed interviews was 4,000.
- To attain the target number of interviews, 6,090 cases out of 7,572 eligible cases were sampled from the 2009-2010 NS-CSHCN.

QUESTIONNAIRE

What is the content of the Pathways survey?

- The Pathways survey consists of both a telephone interview and an SAQ. Both instruments are available online at <http://www.cdc.gov/nchs/slaits/spds.htm>.
- The telephone interview asked respondents about the emergence of symptoms, the context of the original diagnoses, the providers who made the diagnoses, the child's current diagnostic status, the types of clinical treatments/interventions and educational services used to address the developmental problems, and other parental concerns or perspectives.
- The SAQ consists of questions about current symptomatology and impairment levels, as well as children's skills and abilities.

What is the source of the Pathways survey questions?

- Most of the Pathways survey questions were developed especially for the survey to meet various data needs. However, the questionnaire does include several question sets drawn from other sources. For example:
 - Questions on the doctor's response to the parent's concerns (PC7_A), early intervention services (ES10-ES11), and functional limitations (FSD1) were used in the Pennsylvania Autism Needs Assessment (Bureau of Autism Services, Pennsylvania Department of Public Welfare, 2011).
 - Questions on the receipt of standardized, parent-completed developmental screening (PC7_B-PC7_F) were developed by the Child and Adolescent Health Measurement Initiative (Bethell et al., 2011) and originally used on the 2007 National Survey of Children's Health.
 - Questions on parental perceptions (PP2) were adapted from the Revised Illness-Perception Questionnaire modified for autism (IPQ-RA; Anbar et al., 2010).
 - The SAQ includes the 25-item Strengths and Difficulties Questionnaire (Goodman, 1997) in Parts A-C, and the telephone questionnaire includes the brief 5-item SDQ as fielded annually in CDC's National Health Interview Survey. The copyrighted 25-item SDQ permits users to develop generalized scores for conduct problems, hyperactivity, emotional symptoms, peer problems, and pro-social behavior. It also includes questions related to chronicity, distress, social impairment, and burden to others.

- The SAQ also includes the Children’s Social Behavior Questionnaire (Hartman et al., 2006) in Part D. This 49-item questionnaire, adapted (with permission of the author) for use with English-speaking US parents, can be used to describe the severity and pattern of social deficits and other behaviors characteristic of children with ASD, especially in ASD’s milder forms. NCHS is in the process of confirming the validity of scales based on these adapted questions for this population of school-aged US children.

DATA COLLECTION

When were the data collected?

- Pathways telephone interviewing began on February 10, 2011 and ended on May 15, 2011.
- The data collection period for the SAQ was from March 8, 2011 through June 21, 2011.

Who was the respondent?

- The parent or guardian with knowledge of the health and health care of the children in the household who originally completed the 2009-2010 NS-CSHCN detailed interviews. Of these respondents, 80% were the mother (biological, step, foster, or adoptive), 14% were the father (biological, step, foster, or adoptive), and 6% were some other relative or guardian.

What was the average interview length?

- The average telephone interview length for eligible respondents was 37 minutes, 11 seconds, and the median time was 35 minutes, 10 seconds.

How many interviews were completed?

- 4,032 telephone interviews were completed.
- Some parents and guardians who completed the telephone interview did not agree to have the SAQ mailed to them. Of 3,997 SAQ’s mailed, 2,988 questionnaires were completed and returned by mail or were completed by phone. (In the data file, SAQ_MODE identifies the mode of SAQ response.)
- The following table gives the number of completed interviews by the developmental conditions children currently have, as reported by their parents or guardians:

Current CSHCN Developmental Conditions	Count
ASD only	496
Intellectual disability only	46
Developmental delay only	1,441
ASD and intellectual disability	11
ASD and developmental delay	621
Intellectual disability and developmental delay	611
All three of the above conditions	292
None of the above*	514
Total	4,032

* Children in this category are CSHCN who were eligible for the Pathways survey because a doctor or other health care provider had said that the children had one or more of the three conditions, but the parents or guardians reported in the Pathways survey that the children did not currently have any of the three conditions.

What was the interview completion rate?

- Of the parents or guardians with eligible CSHCN, 71% were successfully re-contacted and 87% agreed to participate. The overall weighted telephone interview completion rate, which was 62%, combines both the contact rate and the participation rate.
- The overall SAQ return rate was 75%. The overall weighted SAQ interview completion rate, which was 44%, combines both the telephone interview completion rate and the SAQ return rate
- The overall response rate for the Pathways survey is the product of the Pathways interview completion rate and the NS-CSHCN response rate. See the NS-CSHCN “Frequently Asked Questions” document for more detail about the NS-CSHCN response rate.

How much time elapsed between completion of the 2009-2010 NS-CSHCN and the Pathways survey?

- Re-contact for the Pathways survey took place an average of 9 months after the initial NS-CSHCN interview.

Were parents and guardians offered monetary incentives to participate?

- To improve the likelihood that parents and guardians of eligible children would participate in the survey, a detailed incentive plan was implemented. All parents and guardians were offered an incentive. The value of the incentive to complete the initial telephone interview was \$20-\$25. The value of the incentive to complete the SAQ interview was \$10-\$15.

What non-English languages were used to complete the interviews?

- The Pathways telephone interview and SAQ were administered in English only.

DATA FILES

How many interviews were included on the final data files?

- The publicly released microdata file includes data from all completed Pathways telephone interviews (n = 4,032) and SAQs (n = 2,988).

If respondents were permitted to provide multiple answers for the same question, how is this reflected in the data file?

- When respondents were permitted to provide multiple answers for the same question, a dummy variable was created for each possible answer. The values for these new dummy variables are “1” (yes, this answer was given) and “2” (no, this answer was not given). When respondents could not or did not provide an answer to the question, a value of “6” (don’t know) or “7” (refused) is reported for each of the dummy variables.

What variables were suppressed to protect confidentiality of Pathways participants?

- NCHS takes extraordinary measures to assure that the identity of survey subjects cannot be disclosed. The risk of inadvertent disclosure of confidential information regarding individual respondents is higher with a publicly released data set having detailed geography variables, a detailed and extensive set of survey observations, and a sizeable proportion of the total population of interest. Coarsening a data set by suppressing survey variables, collapsing multiple variables into one, and/or collapsing response categories for other variables are common techniques to reduce the risk of inadvertent disclosure. These techniques have been applied to the publicly available Pathways microdata file to reduce the risk of inadvertent disclosure for children with severe functional limitations, heavy use of clinical services, or unusual patterns in their diagnostic history and service utilization:
 - The ages when the child was first diagnosed with ADHD (DE_ADD2), depression (DE_DEP2), anxiety (DE_ANX2), or behavioral problems (DE_BEH2) have been released only as dichotomous variables indicating that the age of first diagnosis was either 1) before the diagnosis of ASD, or 2) at the same age as or later than the diagnosis of ASD. (The variable is missing if the child did not have a diagnosis of ASD.) The same derived “relative age” variables have also been

created relative to the age of first diagnosis with intellectual disability and developmental delay, if the child had ever been diagnosed with those conditions.

- Information about genetic screening, including whether screening confirmed or revealed any condition (DE18) and the specific condition confirmed (DE19), is suppressed. Whether or not genetic screening occurred (DE17) is available on the public use file.
 - The ages when the child first started using each service (HCS1_X_1A, HCS1_X_1B, HCS2_X_1A, HCS2_X_1B) and each medication type (HCS3_X1, HCS3_X2) are suppressed.
 - The frequency of each service visit (HCS1_X_3A, HCS1_X_3B, HCS2_X_3A, HCS2_X_3B) has been released only as trichotomous variables: 1) at least once per week, 2) at least once per month but less than once per week, and 3) less than once per month.
 - The duration of each service visit (HCS1_X_4A, HCS1_X_4B, HCS2_X_4A, HCS2_X_4B) is suppressed.
 - Information about resource rooms, aides, academic support, and tutoring (ES2 - ES5) is suppressed.
 - Information about activities of daily living and instrumental activities of daily living (FSD1_A - FSD1_I) is suppressed.
 - The number and relative ages of any biological brothers or sisters (DEMO1, DEMO2), developmental conditions diagnosed for any biological brothers or sisters (DEMO3 - DEMO6), the race and ethnicity of the mother and father (DEMO7-DEMO12), and the ages of the mother and father when the child was born (DEMO13A - DEMO15) are all suppressed.
- Most sociodemographic data for Pathways-eligible children were collected as part of the NS-CSHCN. Please refer to documentation for the NS-CSHCN for information about suppression, coarsening, and other edits to the sociodemographic data.
 - The exact responses for all questions requiring verbatim response were also suppressed. However, where possible, the responses were coded back into the available response options for the original questions. Therefore,
 - Responses for PC4_OTHER were coded back into PC4R.
 - Responses for PC7A_OTHER were coded back into PC7_AR01-PC7_AR08.
 - Responses for PC10_OTHER were coded back into PC10R01-PC10R08.
 - Responses for DE_X1_OTHER were coded back into DE_X1R.
 - Responses for DE_X4_OTHER were coded back into DE_X4R01-DE_X4R12.
 - Responses for DE_X7_OTHER were coded back into DE_X7R01-DE_X4R12.
 - Responses for DE_X10 were coded into DE_X10R_01-DE_X10R_12.
 - Responses for DE_X14A were coded back into DE_X13RA-DE_X13RD and directly into DE_X14R_OTHER_01-DE_X14R_OTHER_11.
 - Responses for DE_X16A were coded back into DE_X15RA-DE_X15RC and directly into DE_X16R_OTHER_01-DE_X16R_OTHER_10.
 - Responses for HCS3_G were coded back into HCS3_A-HCS3_F. As a result, some cases that used a medication appear as missing in error (.M) in the follow-up questions on current medication use (HCS3_A_2, HCS3_B_2, HCS3_C_2, HCS3_D_2, HCS3_E_2, and HCS3_F_2). These cases were not asked the follow-up question since they did not initially say “yes” to the medication type question.
 - Responses for INS5_OTHER were coded back into INS5R01-INS5R05 and directly into INS5R07-INS5R14.
 - Analysts interested in working with data that were suppressed may apply to access unmodified data files through the NCHS Research Data Center (RDC). For more information about how to apply for access, analysts may visit the website at <http://www.cdc.gov/nchs/r&d/rdc.htm>.

Can I link the Pathways data file to the 2009-2010 NS-CSHCN data file?

- Data on the publicly released Pathways microdata file can be linked to data for the same child from the publicly released NS-CSHCN microdata files. To merge the Pathways data with the NS-CSHCN household data, sort both files by the household identification number (IDNUMR). Otherwise, to merge the Pathways data with the NS-CSHCN screener and/or interview file, sort both files by the child identification number (IDNUMXR). Once the files are properly sorted, merge them by the identification number used in the sorting procedure.

SAMPLING WEIGHTS

How were the data weighted?

- The Pathways sample was selected from children identified in the 2009-2010 NS-CSHCN as being eligible for the Pathways survey. Therefore, the final child weights from the NS-CSHCN weighting process were the base sampling weights for the Pathways survey.
- Adjustments to the base sampling weights included the following steps and calculations:
 - Adjustment for subsampling within each stratum defined by condition(s) reported in the NS-CSHCN. The six mutually exclusive strata were:
 1. Ever diagnosed with ASD but not currently diagnosed with ASD
 2. Currently diagnosed with ASD
 3. Ever diagnosed with intellectual disability but not currently diagnosed with intellectual disability and never diagnosed with ASD
 4. Currently diagnosed with intellectual disability and never diagnosed with ASD
 5. Ever diagnosed with developmental delay, but not currently diagnosed with developmental delay and never diagnosed with ASD or intellectual disability
 6. Currently diagnosed with developmental delay and never diagnosed with ASD or intellectual disability
 - Adjustment for non-contact of released telephone numbers
 - Adjustment for incomplete condition-eligibility screener at the start of the Pathways telephone interview
 - Adjustment for condition-ineligible cases
 - Adjustment for incomplete age and residency screeners, for age ineligibility, and for residency ineligibility
 - Adjustment for nonresponse to the Pathways telephone questionnaire
 - Raking adjustment of nonresponse-adjusted telephone interview weights
 - Adjustment for nonresponse to the SAQ
 - Raking adjustment of the nonresponse-adjusted SAQ weights

What are the final sampling weight variables?

- WEIGHT_CATI: This Pathways telephone interview weight should be used only when the units of analysis are CSHCN with completed Pathways telephone interviews.
- WEIGHT_SAQ: The Pathways SAQ weight should be used only when the units of analysis are CSHCN with completed Pathways SAQs.

ESTIMATION AND HYPOTHESIS TESTING

Who does this sample represent?

- When survey weights are used, the resulting estimates are representative of the noninstitutionalized population of US CSHCN ever diagnosed with ASD, intellectual disability, and/or developmental delay, as estimated from the 2009-2010 NS-CSHCN.
- These weighted estimates do not generalize to the population of parents, mothers, or pediatric health care providers.
- Due to the limited sample size, the Pathways survey should not be used for state-level estimates.

Do I have to use a special computer program to analyze these data?

- Yes. For proper variance estimation, your computer program must be able to account for the complex sample design structure. Examples include SUDAAN, Stata, SPSS Complex Samples module, WesVar, the SAS SURVEY procedures, and the base program R with the separate SURVEY package.

What variables should be used to estimate variance?

- Stratum identifiers: PSTRAT (Pathways strata for variance estimation) and SAMPLE (telephone sample type)
- Primary sampling unit (PSU) variable: IDNUMR (household identifier)
- Analysts familiar with variance estimation for the NS-CSHCN will note here that PSTRAT is used instead of STATE as a stratum identifier. The limited size of the Pathways sample does not permit variance estimation for some estimates when using both STATE and SAMPLE as stratum identifiers. PSTRAT was formed by systematically combining states in each region into 2-4 strata based on the average weight associated with each state.
- The SAMPLE variable, which reflects the telephone sample type (landline or cell phone), must be included when specifying the sample design. Because of the weighting procedures for the NS-CSHCN, the data files cannot be used to compare children from cell-phone-only households to children from landline households.
- Some analysts may be using statistical programs that only permit the specification of a single stratum variable. These users should define a new variable with 24 levels by crossing SAMPLE (2 levels) with PSTRAT (12 levels). This new variable can then be used as the stratum variable. For example, Stata users can specify only one variable in the strata() option of svyset. This new variable (named here as STRATACROSS) can be created using the following statement:

```
EGEN STRATACROSS = GROUP (PSTRAT SAMPLE)
```

- SUDAAN users can identify both PSTRAT and SAMPLE in the NEST statement. However, SUDAAN users should note that the first variable listed after the word NEST is assumed to be the stratum variable, and the second variable listed is assumed to be the PSU. To properly identify the PSU variable, the PSULEV option must be invoked in the NEST statement as shown here:

```
NEST PSTRAT SAMPLE IDNUMR / PSULEV = 3;
```

Can the data be subsetted before analysis?

- The procedure of keeping only selected records and list-wise deleting other records is called subsetting the data. Most software packages that analyze complex survey data will incorrectly compute standard errors for subsetted data, because subsetting the data can delete important design information needed for variance estimation. Analysts should not subset the data. Analysts interested in examining specific population subgroups (such as children who currently have ASD) must use the appropriate options in their software package (e.g., SUBPOPN in SUDAAN).

WORKING WITH MISSING DATA

How are missing data identified on the data files?

- The SAS data files for the Pathways survey include special missing value codes for analysts who may wish to differentiate between different types of missing values.
 - “.L” (Legitimate skip)—Variable is missing due to valid questionnaire paths based on a previous answer to a root question.
 - “.M” (Missing)—May indicate that the variable is missing due to interviewer or system errors. In addition, all missing values for derived variables (i.e., variables whose response was not directly provided by the respondent) receive a “.M” code regardless of the reason for the missing data.
 - “.P” (Partially completed interview)—Variable is missing because the respondent ended the interview after reaching INS1 but before completing the full interview.
- Data missing because the respondent did not know the answer or refused to provide the answer have been treated differently. A numeric code was used to identify these responses. Typically, unknown answers are coded as “6,” “96,” or “996.” Refused responses are coded as “7,” “97,” or “997.” However, the codes may be different for specific variables; therefore, analysts are encouraged to consult the data documentation and frequency lists to identify the correct codes for each variable. Failure to do so may result in inappropriate calculations, especially for variables measured using ordinal, interval, or ratio scales.

Have missing data for demographic variables been imputed?

- A microdata file is available that contains multiply-imputed demographic data for the Pathways survey. The imputation file includes imputed data for household income relative to the poverty threshold, household size, highest education in the household, primary language spoken in the household, and child's race and ethnicity. The file also contains a flag variable identifying which cases have imputed data. Those without missing data are shown with the original valid values, while those originally with missing data have had those missing data replaced with imputed data. The file contains a set of five imputations for each Pathways data record.
- Analysts can merge this imputed file to the publicly-released Pathways interview file to do analyses that remove the bias associated with differential missingness. Statistical software products such as SAS and SUDAAN can be used to accomplish the analysis while accounting for the uncertainty in the imputation process. To merge the imputed file to the Pathways interview file, first sort both files by the unique child identifier (IDNUMXR), and then merge both files by the same identifier variable.
- For more information about the use of the multiply-imputed data, see the reports and "Frequently Asked Questions" at: http://www.cdc.gov/nchs/slaits/imputed_data.htm.

GUIDELINES FOR DATA USE

The Confidential Information Protection and Statistical Efficiency Act (Section 512b) and the Public Health Service Act (Section 308d) provide that these data collected by NCHS may be used only for the purpose of health statistical reporting and analysis. Any effort to determine the identity of any reported case is prohibited by these laws. NCHS takes extraordinary measures to assure that the identity of survey subjects cannot be disclosed. All direct identifiers, as well as any characteristics that might lead to identification, have been omitted from the data set. Any intentional identification or disclosure of a person or establishment violates the assurances of confidentiality given to the providers of the information. Therefore, users must:

- Use the data in this data set for statistical reporting and analysis only;
- Make no use of the identity of any person discovered, inadvertently or otherwise, and advise the Director, NCHS, of any such discovery (301-458-4500);
- Not link this data set with individually identifiable data from any other NCHS or non-NCHS data sets.

Use of the data set signifies users' agreement to comply with the above-stated statutory-based requirements.

FURTHER INFORMATION

Whom do I contact if I still have questions about the Pathways survey after I read this document?

- We recognize that this summary of frequently asked questions may not provide all of the information that analysts need regarding the design and operation of the survey. If you have further questions, please send an email to slaits@cdc.gov.

How should this document be cited?

- The suggested citation is:

Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey. 2011 Survey of Pathways to Diagnosis and Services Frequently Asked Questions. April 2012. Available from URL: <http://www.cdc.gov/nchs/slaits/spds.htm>.

REFERENCES

- Al Anbara NN, Dardennes RM, Prado-Netto A, et al. Treatment choices in autism spectrum disorder: The role of parental illness perceptions. *Research in Developmental Disabilities* 31:817-828. 2010.
- Bethell C, Reuland C, Schor E, et al. Rates of parent-centered developmental screening: disparities and links to services access. *Pediatrics* 128:146-155. 2011.
- Bureau of Autism Services, Pennsylvania Department of Public Welfare. Pennsylvania autism needs assessment: a survey of individuals and families living with autism. 2011. Retrieved from <http://www.paautism.org/asert/report.html>.
- Goodman R. The Strengths and Difficulties Questionnaire: a research note. *Journal of Child Psychology and Psychiatry* 38:581-586. 1997.
- Hartman CA, Luteijn E, Serra M, Minderaa R. Refinement of the Children's Social Behavior Questionnaire (CSBQ): an instrument that describes the diverse problems seen in milder forms of PDD. *Journal of Autism and Developmental Disorders* 36:325-342. 2006.